THE HEMO HERALD

A Newsletter of the Brandywine Valley Hemophilia Foundation Serving the Bleeding Disorder Community of Pennsylvania, Delaware, & New Jersey

BVHF Mission:

Brandywine Valley Hemophilia Foundation was founded in 1972 and is a totally volunteer organization dedicated to serving the Bleeding Disorder communities of Pennsylvania, Delaware, & New Jersey. We provide:

-Education/Outreach meetings & Events for patients & families

-Funding for local Hemophilia Treatment Centers, Hospitals, & Summer camps

-Education scholarships & Conference Travel Scholarships

-Emotional/Financial support for patients/families in times of hardship

-Advocacy in the political spectrum for the continued needs of the Bleeding Disorder community

-Funding for research for improved treatment & the Hope of a Cure



UPCOMING EVENTS:

March 3: Factor Fluency: Higher Factor Activity Levels Matter, Education dinner at Columbus Inn

March 18: ChristianaCare/AI Nemours Education day

June 10: Spring Wine Tasting/Education Fundraiser

http://brandywinehemophilia.org



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AS **BVHF** STARTS ANOTHER YEAR, WE WANTED TO TAKE A MOMENT TO HIGHLIGHT ALL THE AMAZING EXPERIENCES WE HAD TOGETHER IN 2022!

EDUCATION MEETINGS, SPRING EDUCATION/WINE TASTING FUNDRAISER, BLUE ROCKS BASEBALL, FISHING EXCURSION, 5K FUNDRAISER, EDUCATION/PAINTING WORKSHOP, & OUR ANNUAL HOLIDAY EXTRAVAGANZA!



We at BVHF believe that our job is to help educate, support, & encourage our fellow bleeding disorder members to strive to achieve the greatest degree of physical & mental wellness possible. We never suggest any specific drug company, specialty pharmacy, or product to be the best for anyone. Instead, we hope to provide you with the information on <u>ALL available options</u> so that in partnership with your physicians/HTC, you can find the best fit for you and/or your loved one(s).

The Brandywine Valley Hemophilia Foundation would like to thank the following companies for sponsoring our foundation in 2022 and helping achieve that goal.





The *KEY* ingredient to wellness is prevention. We all have busy schedules, but no one has time for an unexpected illness or hospitalization. Many times, significant and severe health complications can be prevented through routine screening visits. Make sure you are scheduling an annual physical exam with your Primary Care physician. Follow up with your Hematologist/HTC including yearly physical therapy assessments. The American Cancer Society recommends the following:

Yearly Physical Exams

Colonoscopy for all individuals 45 years and older Mammogram for females 40 years and older Dental checkups every 6 months for all ages GYN/PAP screenings every 3 years for females ages 21-65 years

BVHF 2023 Student Scholarship



BVHF is pleased to make available a \$2000.00 scholarship to an individual impacted by hemophilia or other significant bleeding disorder. Once chosen as the recipient, the scholarship will be renewed each year for four years as long as the individual remains in good academic standing. A check will be made payable to the educational institution and mailed to the recipient each year following verification of continuing education and an adequate academic record. Any post-secondary educational opportunity will be considered for funding. CHECK THE WEBSITE FOR FULL DETAILS AND APPLICATION.

Who Can Apply

- Any individual within our service area who has been diagnosed with hemophilia or other significant bleeding disorder. Evidence of this diagnosis must be provided by your clinician or HTC
- Any individual within our service area whose immediate family member is attached to the hemophilia/bleeding disorder community. Evidence of this must be provided by your clinician or HTC.

DEADLINE FOR APPLICATION: May 26, 2023 NOTIFICATION OF ACCEPTANCE: June 23, 2023



March is Bleeding Disorder Awareness Month. Do you talk about you or your loved one's bleeding disorder with other family, friends, coworkers? Help spread awareness by posting on your social media account(s) regarding bleeding disorders. Don't be afraid to share your story!

Watch a quick YouTube video on Bleeding Disorder Awareness. https://youtu.be/fNvyNncFmO4





ChristianaCare & AI Nemours Children's Health

Delaware Hemophilia Treatment Center

Bleeding Disorder Education Day

March 18th, 2023

8:00 am – 1:00 pm

ChristianaCare – Newark Campus – John Ammon Education Building

Please use the link or QR code to pre-register

https://forms.office.com/r/NaRRne7bCm



Saturday June 10, 2023 Spring Wine Tasting/Education Celebration



Please join the Brandywine Valley Hemophilia Foundation for a late afternoon gathering including Raw Bar and Hors D'oeuvres, Educational Exhibits and speeches, raffle tickets for prizes. \$100/per person.

A discount is available for patients with a bleeding disorder or their caregivers: \$60 per person

Fieldstone Golf Club 1000 Dean Road Greenville, DE 19807

*This event is for age 21 or older

RSVP to Board Member and Chairman of this event: Stephen Steinmetz 610-235-1229.

Want to help the BVHF Spring Raffle Fundraiser?



Contact Jennifer Davis if you would like to donate: Jenny2Davis@gmail.com or 302-312-6244



HFA NEWS

Spend a Summer in DC/Internship

Each year, HFA offers internships to qualifying students and provide them with leadership, guidance, housing, and a stipend. College students or recent graduates who are 18 years of age or older and a) have a bleeding disorder or b) are related to a person with a bleeding disorder are eligible to apply. Learn More and Apply

Application Requirements

- Available to travel to and live in Washington, D.C. for 10 weeks
- Available to work 30 hours per week
- Currently enrolled in (or just previously graduated from) college or university
- 18 years of age or older
- Have a bleeding disorder or be related to a person with a bleeding disorder
- Have a demonstrable interest in policy, government relations, and/or advocacy work, including but not limited to prior experience or pursuing a degree in political science or a related field of study
- Excellent communication, writing, and research skills



National Hemophilia Foundation:

8/17/2023-8/19/2023: NHF's 75th Annual

The 75th Annual Bleeding Disorders Conference (BDC) will take place from August 17 to 19, 2023 at the Gaylord National Resort & Convention Center in National Harbor, Maryland. Located on the historic Potomac River and within short distance of national landmarks in nearby Washington, DC, this will be the perfect setting for BDC 2023 as we mark the 75th anniversary and embark on a new phase of the organization and bleeding disorders community.

BVHF is offering an opportunity to fund attendance to the National Hemophilia's Bleeding Disorders Conference for 2 individuals, or a child and parent, whose lives are connected to the hemophilia/bleeding order community. Registration, travel and lodging expenses for three (3) nights for the Annual Meeting will be covered for those whose applications are selected. It will be the responsibility of the individuals chosen to arrange their own travel and lodging, as well as registration for the Conference. Brandywine Valley Hemophilia will refund the expenses. Other arrangements might be made on a as needed basis. Registration, travel, and lodging expenses for a maximum of \$1000 will be paid for those whose applications are selected.

For more information on the BVHF grant, including eligibility requirements and how to apply, <u>download</u> <u>application</u>.

Brandywine Valley Hemophilia Foundation proudly supports among the many HTC's within Delaware, Pennsylvania, & New Jersey...**DRAGONFLY FORREST SUMMER CAMP**. Camp Dragonfly offers a one-week special summer camp for kids with bleeding disorders who are between grades 2-10. This year's camp will be August 6-11, 2023. If you are interested in having your child attend this summer camp, contact our foundation for information regarding application and scholarship assistance.

Check out our Website updates at <u>www.Brandywinehemophilia.org</u>

Make sure to follow us on Facebook & tag us in any photos from our events!

*If you are interested in having advertising space to sponsor our next Newsletter, contact GVannicola@verizon.net

Do you have recommendations/requests of what you would like to see in our next Newsletter? Contact

Jenny2Davis@gmail.com